CNICS Data Sharing Policy

The CFAR Network of Integrated Clinical Systems (CNICS) uses a collaborative cohort study design to gather unique data on the clinical, virologic, immunologic, behavioral, metabolic, service utilization, and psychosocial aspects of HIV infection and disease. CNICS intends that key findings from this collaborative cohort study be shared within CNICS sites and with outside investigators and be presented and published widely, promptly, and be of the highest quality. CNICS supports NIH's data and resource sharing policy according to the following provisions outlined below.

- In keeping with the intent of CNICS, all leadership agree that resources which house data serve as repositories of study data to be shared with investigators according to established SOPs available on our website or by request.

- For data and methods not available via the website, leadership has oversight for determining who can receive such, determine conditions placed on the use of data, and determine the modes of sharing.

- In accordance with University policy, all data sharing involving human subjects must comply with stated HIPAA regulations.

- The sharing and archiving of Human subjects data will be executed in a manner that ensures patients' confidentiality and right to privacy. As such, all patient identifiers will be removed prior to release of human subjects data for sharing.

- CNICS encourages collaborators who are not members of CNICS or partner institutions to be involved in data and/or laboratory analyses. Collaborators are required to acknowledge that CNICS data and specimens are the property of the individual CNICS sites. Collaborating scientists will be encouraged to raise relevant scientific questions beyond the data analysis as contracted by CNICS; requests for approval for data analysis, presentation, or publication must follow the principles outlined in our established policies (SOP). Outside investigators should name a CNICS contact person whose responsibility is to ensure the lead investigator has had the opportunity to share his/her ideas with the working groups. Proposals will follow the same review process and publication policies as outlined in our SOPs. CNICS investigators will have the option to publish results of the analyses if the outside investigator does not wish to write up the study, but agrees that a publication is worthwhile.

- The CNICS Proposal Development and Publication Policy (SOP) has been developed to ensure that these important multi-center research findings from CNICS be developed collaboratively, efficiently and equitably. Additionally, it is the purpose of this policy to ensure an efficient, fair and coordinated collaboration with other outside investigators or other cohort studies on all research questions deemed appropriate for joint analysis.

- All Core procedures, methods, SOPs, etc. are made available to the public available via our website http://www.uab.edu/cnics. This includes data from pilot projects and CFAR-supported repositories/databases.

- Inquires regarding access to datasets or specimens are done using specific web forms available on the CNICS website homepage (www.uab.edu/cnics). Questions may be forwarded to the CNICS Administrator (Dr. Porter).

- All manuscripts which are published in peer-reviewed literature conform to NIH policies regarding access to both the manuscript, the primary data, and key materials (eg. Clones, reagents) used in the conduct of the studies.